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ABSTRACT

Provided in the first of four booklets on citizen advocacy for the mentally retarded is a general introduction to the concept. Advocacy is defined and traditional approaches including institutional practices are reviewed. The individual advocate-protege relationship is seen to be the central feature of the citizen advocacy model serving mentally retarded people in institutions, in transition from the institutions, and in the community. Potential advocate roles include companion, guardian, and adviser. The support structure at the local and state levels is analyzed. The booklet concludes with a brief review of legislative and social factors responsible for current interest in advocacy. (CL)

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Citizen Advocacy for Mentally Retarded Children An Introduction

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Avenues To Change

Book I

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CITIZEN ADVOCACY FOR MENTALLY RETARDED CHILDREN

AN INTRODUCTION

BOOK I

This series of materials was developed in conjunction with the NARC Project **A National Citizen Advocacy Model for Mentally Retarded Children,** Grant #OEG-0-72-5311, which was supported jointly by the Bureau of Education for the Handicapped, National Institute of Mental Health, and Rehabilitation Services Administration of the United States Department of Health, Education, and Welfare.

National Association for Retarded Citizens
February, 1974

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PREFACE: BOOK I

Because of the potential benefits of providing individual Citizen Advocates for mentally retarded children, and due to the increased national interest in such programs, the National Association for Retarded Citizens applied for and received a federal grant for a nation-wide Citizen Advocacy Project which began in August of 1972. Funding agencies were the Bureau of Education for the Handicapped, the National Institute of Mental Health, and the Rehabilitation Services Administration of the U. S. Department of Health, Education, and Welfare.

As a demonstration project, the staff developed a prototype for establishing Citizen Advocacy programs using the concept originally evolved by Dr. Wolf Wolfensberger, expanding and slanting it for utilization by ARCs wishing to implement such programs. However, it is hoped that groups representing other developmentally disabled persons will also be able to benefit from this model.

The primary objectives for NARC's four-year Project were: 1) to develop printed and audio-visual materials which would increase public awareness of and interest in Citizen Advocacy; 2) to gain commitments to establish Citizen Advocacy programs for mentally retarded persons across the nation; 3) to evolve standardized training materials so that local and state advocacy offices could be set up by ARCs, advocates could be recruited and trained, potential proteges could be identified, and these two groups could be matched on a one-to-one basis; 4) to provide direct consultation to ARCs interested in establishing model programs; and 5) to set up a demonstration Citizen Advocacy program in each of NARC's six regions in order to study and document the effectiveness of the model as presented in the materials.

The Project Staff developed a training package consisting of a 14½-minute color-sound 16mm film on Citizen Advocacy, a 20-minute slide presentation on advocate roles, a brochure a workshop training manual, an advocate training resource book, and this series of four books which provide a comprehensive overview of the conceptual and programmatic aspects of Citizen Advocacy. The titles of the books and intended audiences are listed below:

Book I — **Citizen Advocacy for Mentally Retarded Children: An Introduction** — an introduction to the concept for a general readership.

Book II — **Implementation of Citizen Advocacy Through State and Local ARCs** — guidelines for implementation and operation by ARC staff members, advocacy coordinators, and others intersted in starting programs.

Book III — **Effective Advocacy** — a learning tool for the advocate himself.

Book IV — **YOUth as a Citizen Advocate** — for teenagers interested in becoming Youth Advocates.

Those interested in the concept and in volunteering as advocates should read Books I and III. Coordinators should study the entire set. Teenagers should read Book IV. (They may also wish to read Books I and III.) For the most thorough understanding of Citizen Advocacy, the interested persons should read all four books.

These books were developed through a series of steps including research; on-site visits to Citizen Advocacy programs; and review by consumers, key NARC volunteers and staff, the Project's National Advisory Committee, and persons actually involved in Citizen Advocacy at the time of the writing. Modifications and revisions in these books will be made available to the public as new information is compiled.

It is hoped that Books I-IV will provide the reader with all the knowledge needed to become a part of the advocacy effort. For further information regarding other available materials, contact:

National Association for Retarded Citizens
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Arlington, Texas 76011

BOOK I

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CITIZEN ADVOCACY FOR MENTALLY RETARDED CHILDREN: AN INTRODUCTION

Think back to your childhood and remember those special people — the ones who helped you over the rough spots and shared important events which wouldn't have been as significant if they hadn't been shared.

This person may have been someone your own age who understood how you felt and helped you realize that you were really like other people after all . . . someone you could count on if you ran into trouble. Or, he or she could have been an older person outside your family circle who taught you to be more self-sufficient and made you feel like an important individual.

As you grew older, many of these special people probably touched your life. They may have been best friends, professors or coaches, that certain Sunday School teacher, a specific neighbor. They were the ones who helped you with the more serious things in life, such as knowing how to act in public, getting a driver's license, holding your first job, and making plans for the future. Even when you were alone, they seemed to be with you, giving you a feeling of support and confidence.

Some children, however, grow up essentially by themselves. Suppose instead of having been a typical child with a family and friends to back you up, you had been a mentally retarded child in an institution where each day's activities are pretty much the same as the next, and where you were forced to share the attention of a few persons with forty other children. Your life would have been arranged entirely with the group in mind, and it would have seemed easy to feel that nobody really cared. It's just one short step from feeling that way to not caring about yourself as well.

Suppose that you had never received a phone call or a letter from a friend. Suppose, even if you had, no one had ever shown you how to write a return letter and mail it or how to place a call by yourself. Suppose you had never been to a movie in town with a friend, never been on a public bus, never had the opportunity to hold a job, never known that if you fell into trouble, there was someone around who would pick you up and dust you off. How would you have felt then?

If you are able to contrast feelings of security and belonging with those other emotions of loneliness, frustration, boredom, fear, and isolation, you already have a pretty good idea of what Citizen Advocacy is all about . . . it's about providing a more normalized life for all mentally retarded people through personalized relationships.

A DEFINITION OF CITIZEN ADVOCACY

By definition, Citizen Advocacy for mentally retarded persons is basically a one-to-one relationship between a capable volunteer ("advocate") and a mentally retarded person ("protege") in which the advocate defends the rights and interests of the protege and provides practical or emotional reinforcement (or a combination of both) for him. All of this occurs within the framework of a structured advocacy system.

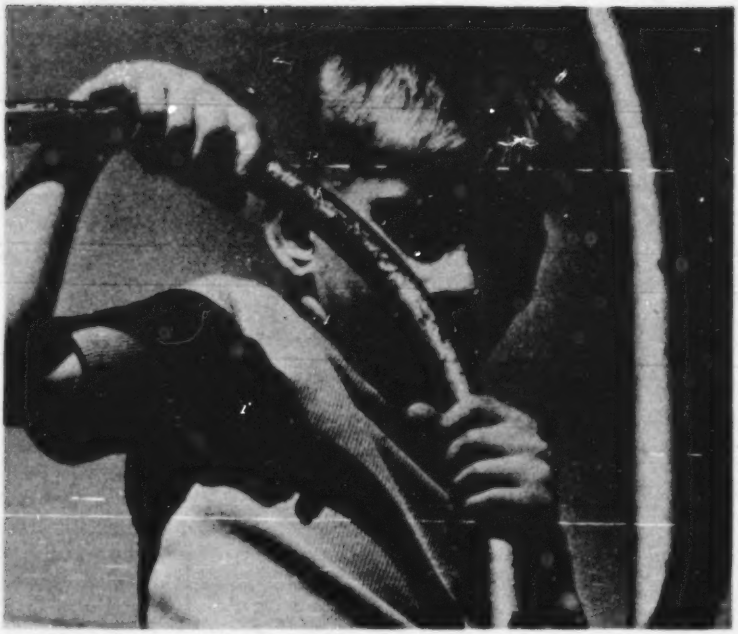
This definition can be broken down part by part in order to further clarify its meaning. **"A one-to-one relationship"** is simply explained. It means that two people relate to each other on a continuing, personal basis. It is not a dependency relationship, but rather a mutually beneficial one.

A **"capable volunteer"** is a person who is well-adjusted, established in the community, and able to form successful relationships with other people, and he has empathy, patience, and commitment to his protege. He is not a "do-gooder" who seeks to boost his own ego. His goal is to help his protege widen his horizons and become as self-sufficient as possible.

The **"retarded person or protege"** is one who develops consistently at a below average rate and experiences unusual difficulty in learning, social adjustment, and economic productivity. These people are more like you than they are different from you, and they have a great deal to offer to advocates who will take the time to get to know them. Just like the rest of us, mentally retarded persons are limited in some areas of progress, but they are each unique, developing individuals.

An advocate **"defends the rights and interests of the protege"** by being a spokesman for him when he cannot speak for himself, intervening in his behalf, making sure that his retarded friend is receiving all the benefits and services to which he is entitled, and helping discover avenues for his protege's self-expression. The advocate is involved to the extent that he feels his own rights as a human being are being infringed upon if the rights of his protege are being denied or abridged. This representation can take the form of running interference for a protege who may be getting into a legal or financial situation that is beyond his coping abilities, or it could also mean making sure the protege is represented in court if a serious threat to his rights exists.

The advocate may provide **practical** guidance for his protege by giving him knowledge of the rudiments of daily living. This help may range from learning to tie shoelaces to planning a budget, from mailing a letter to landing a job, from shopping to making matrimonial decisions. You may also hear this kind of back-up



referred to as "instrumental" help and it is geared toward increasing the independence of the protege.

The advocate may also offer **emotional** reinforcement to the protege. For example, he may provide attention and affection for a mentally retarded person who may or may not have a family and friends of his own. This aspect of advocacy means caring about the protege, and letting him know you care. All of these things are aspects of friendship, and are ways of meeting "expressive needs".

The **"framework of a structured advocacy system"** refers to Citizen Advocacy Offices which are developed to offer training, guidance, and support to the advocate. These offices are established on state and local levels to locate retarded children needing help, and to find potential advocates, and then to screen and match these two groups on an individual basis. Special kinds of back-up are offered to enable the advocate to fulfill his role in the best possible way while still protecting him from legal, financial, or emotional liabilities.

The local office is ideally headed by a full-time coordinator who orients, reinforces, and supervises the advocate. Supervision is kept to a minimum so that the advocate is allowed the freedom to use his own resources and ideas in serving his protege, but the advocate is not expected to be a "junior caseworker" and handle every

situation by himself. He is given supervision in the sense that his work is monitored, and, through the office, he has contacts with specific persons who can offer help. He does not receive monetary compensation for his services; therefore he operates free of conflicts of interest, and he is different from the traditional volunteer in that he is a volunteer to a specific person, not to a program or service agency.

The Citizen Advocate will find that he has chosen a highly satisfying and fulfilling role for himself. He knows that he is providing a service involving personal concern that is not currently afforded by any other group or agency. He realizes that he is contributing more to doing something about the human problems he sees around him than just giving to charities or paying taxes. And, he experiences the human rewards of a personal relationship with the protege.

Advocacy is a direct personal involvement in the life of another human being, whether it means offering practical advice, emotional support, or both. Through the Citizen Advocate program, a volunteer can learn something about the field of mental retardation, and, since various socio-economic and ethnic groups may be involved, he will have a chance to see clearly into the lives of people whose culture may be very different from his own.

For those who are considering careers in the field of mental retardation or other related areas, or who are already in training for such occupations, advocacy offers an opportunity to test their interests and capabilities; and for those who are currently involved in careers outside this realm, the program offers an outlet for the expression of concern about ensuring dignity and fulfillment for handicapped individuals.

TRADITIONAL FORMS OF ADVOCACY AND A NEW APPROACH

The idea of advocacy is by no means a new concept. Throughout history, men have appointed other men to act as their spokesmen. Lawyers are frequently indicated as examples of advocacy because they voice another's cause.

Some methods of advocacy have been more effective than others. Those who are knowledgeable about the subject have studied systems conceived in the past for protection and representation of the general populace and are aware that all methods share both strengths and weaknesses. A model for Citizen Advocacy was developed by Dr. Wolf Wolfensberger (1969) in an effort to minimize problems found in protective service systems and to help establish a more effective means of safeguarding the privileges and interests of handicapped or disadvantaged persons.

Parents as Advocates

Parents are a good example of one type of advocacy at work. From the infant's birth, they are responsible for meeting his needs and securing his rights. Parents are expected to take care of both the physical and emotional sides of their children's development, and it is the mother and father who have a major role in socializing the child into the environment and culture. As the child grows up, the practical aspects of providing for him lessen, but the emotional ties still linger. When a child does not have living, functioning, or caring parents, society has devised other advocacy substitutes for him. Foster parenthood, guardianship and adoptive parenthood are examples.

The case of the retarded child may be somewhat different. In adulthood, he may still require a higher level of both emotional support and practical help. This does not, however, indicate that he remains child-like; it only means that some of his developmental needs are greater for a longer period of time (perhaps even after his parents' death), than those of a non-retarded adult.

ARCs as Advocates

One of the most vital examples of advocacy in action today is found in the state and local Associations for Retarded Citizens which are banded together as the National Association for Retarded Citizens. NARC (formerly the National Association for Retarded Children) was founded in 1950 by 42 parents representing 23 local chapters, and since that time its state, local, regional and national components have been filling advocacy roles for mentally retarded children. This is the only voluntary organization devoted solely to promoting the welfare of retarded persons, and its wide-spread network of locations with a membership of 245,000 adults in 1,500 state and local chapters (along with 20,000 Youth NARC members in over 500 units of their own) makes NARC a natural mechanism for implementing the Citizen Advocacy concept for mentally retarded children.

With their commitment to retarded children and adults and their independence from public service agencies, local ARC units are in a prime position to be focal points for grassroots Citizen Advocacy Programs, and state ARC's are in an advantageous situation to coordinate and support these activities on a state-wide basis.

Reports from 540 ARCs ("NARC Membership Characteristics and Growth," Vol. 1, #2, Jan. 1, 1971) indicate that about 60 percent of the membership consists of parents or relatives of retarded persons, while 15 percent are professionals working in this field, and 25 percent are other interested members of the community. Citizen Advocacy Programs are an excellent opportunity for ARCs to

attract additional membership, increasing the percentage belonging to the latter group, and introducing "new blood" into the ranks.

In the early history of the ARCs, parents themselves collectively provided the necessary services for their children, but as time passed, they began to develop the belief that, as an influential group, they could band together and demand that their children be supplied with the same services granted other children by governmental and educational systems. They have been successful in getting legislation passed to provide for a wide array of services for their children in a community setting. The Citizen Advocacy Program now offers them the opportunity to gain additional support for these efforts.

The Ombudsman System

One historical example of advocacy which is still in operation today is the Ombudsman System. This social and legal activity began over 160 years ago in Sweden. The traditional Ombudsman role is to investigate complaints from citizens who feel they have been dealt with unjustly by government departments, and to seek redress for the plaintiff. Ombudsmen are instruments of legislative bodies, but are outside of the administrative structure. They have access to official papers bearing on their cases, but they can only recommend a change in the matter involved — they cannot enforce, or overrule a decision made by their governmental counterparts. The Ombudsman is an impartial and objective investigator who benefits both the people and the governmental bodies. He is looked upon as the conscience of the State because he reminds people in government offices that they are there to serve those who elected them.

Most people who have grievances find it difficult to go through the maze of procedures required under law to initiate change — they don't know where to start, how to bear the expense, or how to ensure quick action. This is where the Ombudsman fits in. He can give more rapid attention to the problem and knows how to go through channels to obtain the desired goal, and he can recognize patterns of complaints that call attention to a larger condition that may need investigating. The Ombudsman therefore helps to keep the balance between the ever-widening boundaries of government administration and the citizen's rights. States who have benefited from the Ombudsman Systems are Hawaii, Oregon, Iowa, Nebraska, and South Carolina.

There are many advantages of the Ombudsman system; however, the disadvantages are just as immediately obvious. To begin with, this system works best in locations where it is needed least. For example, only where the general public and its administrators are already committed to promoting fairness in public dealings

can the Ombudsman receive the support necessary for him to carry out his duties most effectively.

And, since such a heavy workload falls squarely upon the shoulders of one man who must direct and carry out the work (with or without an assisting staff), personal service is virtually impossible. According to Iowa's Ombudsman, Lawrence Carstensen (**Channels,** 1972), "Government is so big, it's impossible to be expert enough in every field." There just isn't enough time in the day to handle all the complaints.

Only a very small percentage of the cases handled by Ombudsmen involve mentally retarded people. In Sweden, for example, a country that is noted for its Ombudsman system and its concern for retarded persons, out of the 3,531 new cases handled by the Ombudsman's office in 1971, only three involved mentally retarded persons (Graf, 1972). The necessity of citizens knowing their rights and independently contacting the Ombudsman themselves may account for the unusually small portion of mentally retarded persons being served by an Ombudsman office.

In addition, since the Ombudsman is paid by the government, there is always the possibility that conflicts of interest may arise when the citizen challenges the state through him. The Citizen Advocate, on the other hand, is a free agent, and as a private citizen matched to a mentally retarded person on a one-to-one basis, he can devote more time and energy to his protege.

INSTITUTIONAL AND AGENCY SYSTEMS

Some of the oldest methods of endeavoring to protect the interests and well-being of retarded children and adults in this country are its residential facilities for the mentally retarded, physically handicapped, or orphaned; and municipal or county agencies such as child welfare and child development clinics. Some of the same problems of individualizing service encountered in the Ombudsman system also hinder institutional and agency systems in their advocacy roles.

Institutional Problems

Institutions for the mentally retarded have existed in this country since the 1850's. The first such residential facilities were designed to provide habilitation of residents in order to return them to the community. Residents did not leave their communities for such training since facilities were integrated with the cities served.

Within a few years after the construction of America's first institutions, an intense concern for the "protection of society" emerged and residential facilities were very soon located farther and farther away from the general populace, while institutional populations

simultaneously became larger and larger. Social attitudes gradually evolved so negatively that adequate funding was not provided for the operation of residential centers, and they thus became dehumanizing warehouses in which residents were utilized as captive work forces to operate dairies, tend stock, or raise vegetable gardens.

Most institutions of today no longer utilize these kinds of self-support, but some peonage still exists along with other conditions such as large populations, isolation from communities, overcrowding, lack of training and education, inadequate operating funds, etc. In fact, many of the problems inherent in the structure and design of facilities at the turn of the century can be easily detected in some institutions currently being built.

A report highlighting some major problems in residential facilities was compiled and published by David Rosen and Marvin Bruno (1971). The research was supported by the President's Committee on Mental Retardation and sponsored by the National Association of Superintendents of Public Residential Facilities.

The study reflected a survey of approximately 68 percent of the public residential facilities in this country. It revealed that most residential facilities were too large, and that their programs tended to be impersonal and group oriented. The average residential facility had a capacity for 1,000 residents; and in addition to being overcrowded, a minimum of privacy was indicated. Sixty-eight percent of the residents lived in structures which had 21-75 beds per room. Such a situation goes beyond privacy; a very abnormal living setting and life style naturally follow. To add to this, most institutions function with inadequate numbers of staff, and many of these are undertrained.

The practices within many residential facilities are abnormal and dehumanizing. Daily routines — getting up in the morning, dressing, eating, bathing, going to bed — are too often group oriented, regimented, and impersonal in order to serve the needs of the staff, rather than those of the residents. Unusual discipline or control techniques are also frequently found. The study indicated that eighty-one percent of the institutions surveyed used mechanical restraints like restraining jackets, or arm and wrist bands.

Many of the problems within residential facilities are also related to denial or abridgment of basic rights of residents as citizens. The study indicated eighty-one percent of the surveyed facilities did not pay minimum wage to resident workers; eighty-six percent had no registered voters; and eighty-one percent did not afford the opportunity for residents to make private telephone calls.

It is encouraging to note, however, that many public residential facilities are seeking to improve services and to involve consumer representatives and volunteers more meaningfully in planning, implementing and monitoring of services. Parents and guardians have

traditionally been involved on the fringes in the sense that they have participated in volunteer-type programs, fund raising, and public relations. However, trends have indicated that the roles of parents, guardians, and volunteers can be expanded to include more effective participation in decision and policy making, lobbying for adequate budgets, and actually taking part in the delivery and evaluation of services to residents.

Positive change in residential facilities is greatly dependent upon active consumer representation. In the past, the staff of facilities has practiced self-evaluation regarding the rights and dignity of residents, and this method has not been adequate or effective. Someone with an objective viewpoint must represent residents when their rights and dignity are violated or diminished. Ideally, this person should be the parent or guardian, but they have not been encouraged to monitor services and programs, and, in many cases, they have not been critical because they felt threatened by the possibility of reprisal in terms of diminished services for their children. Although there is generally little basis for such fears, residential placement has been their only option, and until recently there has been no strong desire to "make waves."

Advocates can assist parents and guardians by playing an important and effective role in safeguarding the rights and dignity of residents, as well as actively seeking positive change in residential facilities. The advocate may be in a position to realistically evaluate the situation of the resident and represent his rights and interests. Of course, advocates are particularly needed for residents who do not have regular contacts with a parent, guardian, or friend.

Protective Services Problems

Protective strategies, and agencies which provide these services, were also developed around the turn of the century to help remedy abuse, abandonment, and exploitation of handicapped individuals, particularly children. As indicated earlier with regard to institutions, handicapped persons, especially the mentally retarded, were believed to be harmful to society, and so they were shunned and segregated from their fellow human beings. As the period of fright ended, a number of well-intentioned plans were developed. These strategies included such legal arrangements as guardianship, foster parenthood, adoptive parenthood, conservatorship and trusts, as well as human service agencies responsible for arranging these relationships and the laws and practices which govern them.

Many early protective service approaches involved public guardianship where the court, the administrator of an institution, or a human service agency exercised control over the retarded person. This public guardianship sometimes turned into public custody, and the child would end up in an institution when he didn't necessarily belong there. It is often not in the best interests of mentally

retarded residents when the administrator of a facility acts as a personal guardian. There are many instances when conflicts can arise between the rights of residents and the duties of the administrator, such as the necessity of his reducing staff or eliminating programs for reasons of economy or overcrowding.

The shortcomings of protective service agencies are evident. Since it is often difficult to represent a client and serve him on a highly personal basis at the same time, these social service-type agencies mainly provide tangible help for their retarded clients. They are usually most concerned with activities like ensuring Social Security benefits for a client or placing him in a foster home situation. They do not and cannot be expected to cope with the day-to-day problems that can arise in the life of a retarded individual. For example, they are not expected to be on hand to help a retarded man learn the correct bus route that will take him to his job, and they probably could not be called upon to drive a sick child and his parents to the emergency room at the hospital in the middle of the night.

Due to the large volume of cases handled by each staff member, the rapid turnover of personnel, and the compartmentalization of duties performed, a personal, on-going relationship is unlikely to develop between the child and the staff member. For example, after having been shuffled from one agency to another because his case seems to slip "between the cracks" or boundaries of services offered by the various alternatives, a child will finally be referred to one specific agency. There he may be interviewed by one person, diagnosed by another, and actually served by a third, making continuity of relationship or long-range planning virtually impossible. It is sadly true that "the client is usually the last consulted concerning his own future." (President's Report, "White House Conference on Children," 1970.)

Because many agencies have rigid bureaucratic structures, they deal with emergency situations in much the same manner as they handle more routine matters. The client generally must follow a "standard procedure" of contacting certain staff members, filling out papers, and waiting for some action on the part of the agency. Thus, when the needs of an individual arise outside regular office hours or on week-ends and holidays, alternate sources of help are needed if any aid at all is to be obtained.

A further dilemma arises when the interests of the retarded client clash with those of the agency. It is human nature to protect oneself; and if a professional is placed in a situation where his career interests conflict with speaking out against his agency's practices in order to best serve the client, he will find it difficult to be disloyal to his employer. Thus, the interests of the client often take second place to those of the agency. Methods through which professionals acting as private citizens can serve as highly effective advocates will be discussed later in the book, but it is clearly seen

here that a professional in the protective services system cannot simultaneously represent a client in the context of the agency framework and still serve that same individual in a day-to-day advocacy relationship.

An additional problem area in the agency services system arises in the self-evaluation phase of the work performed. Particularly in the United States, agencies have been given the privilege of self-review which is often not effective in the long run unless it occurs in conjunction with an objective review process. In order to make its own services "sound good," agencies may come up with "paper programs" which are workable in theory, but not in practice. This kind of reporting and self-review takes valuable time away from agency personnel which could better be spent with the clients, and it also misrepresents the actual services being provided.

In studying institutional and protective service systems, one can readily see how the Citizen Advocacy concept is of great value and how it does not duplicate services already offered, but provides help over and above that which is afforded by existing approaches. While these institutions and agencies can dispense a certain amount of practical help to their clients, they cannot adequately meet their emotional needs. The advocate, on the other hand, is in the position to spend time with his protege, get to know him gradually, and fulfill his needs in the best ways he can find. The advocate can be called upon in crisis situations to render immediate assistance, and he can act as a spokesman for his protege to ensure that the child receives all the services and legal rights to which he is entitled. Thus, the advocate does not cover ground already tended by existing programs — he provides a personal concern and a consistent, unwavering support for his protege in order to safeguard respect for the human dignity of all retarded persons.

THE CITIZEN ADVOCACY MODEL

The core of the Citizen Advocacy idea is the individual advocate-protege relationship. It is estimated that three percent of the population of the United States will at some time in their life function in the mentally retarded range. Hence, more than six million Americans will fall within this group. (Tarjan, et al, 1973.) The majority of these persons could conceivably benefit from having advocates.

Qualifications of Advocates

What are the qualities that advocates, who will enter into close, personal relationships with proteges, need to possess? The advocate is not just a mediator. He actively represents someone who may not be able to fight adequately for himself. He should be an individual who is able to get along well with a variety of people

and who can serve as a model for his protege. He should not be planning a move to another city in the near future because this would endanger the continuity of the relationship. His life style should be generally socially acceptable and he should have a true belief in advocacy. Sound like an angel? He's not. He is you and your next-door neighbor, or any competent citizen volunteer who is willing to roll up his sleeves and work for a better understanding of retarded people, clear his throat and speak out for their rights, and open his mind and heart in an effort to fill his protege's needs. He must have the patience and the empathy to share both the frustration and the joy in accomplishment of the mentally retarded person. He must accept his protege for who he is today and who he can become tomorrow.

Groups of Retarded Persons Needing Advocates

Advocacy services should be designed to meet the needs of three main groups of mentally retarded persons:

- those residing in institutions on a short or long-term basis;
- those leaving the institutional setting to live on an independent or semi-independent basis in the community;
- those of all ages and functioning levels who always resided in the community.

The needs of these individuals may vary considerably, depending on the appropriateness and adequacy of education and training and the degree to which they have maintained contact with the mainstream of society.

Institutional Residents

Most, if not all, of the 200,000 mentally retarded residents of public institutions in the United States could benefit from advocacy services. As was pointed out in a report mentioned earlier (Rosen and Bruno, 1971), sixty-one percent of the residents in a sample of public institutions were regarded as needing long-term services. Most institutions included profoundly retarded residents in these statistics. Traditionally, these residents will remain indoors with few activities, receive little individual attention, and have restricted or inappropriate programming.

Since a custodial care approach is still prevalent in institutions, activities are frequently focused mainly on providing food, clothing and shelter — and there is little time left over for individualized affection or attention. It is also unfortunate that many personnel who work with residents are so involved in group-oriented rou-

tines that they do not interact with them on a personal basis when time permits. This may be a result of attitudes held toward residents (i.e., "they only need physical care" or "they are incapable of learning self-help"), or the way in which personnel are trained. But the major portion of any work day for direct care staff is, in many cases, devoted entirely to dressing, bathing, feeding, and diapering residents in a highly impersonal and mechanical manner, regardless of the resident's ability or potential ability to do these things for himself.

Custodial care approaches and warehousing cannot result in adequate education or treatment. Under such conditions, those in institutions are forced to live dependent, non-productive lives, while costing hundreds of thousands of dollars per resident for a lifetime of futile existence, boredom, and loneliness.

In addition to increasing personal attention in the life of an institutionalized child through visits, calls, letters, and occasional outings, the advocate can help safeguard the rights of these children by ensuring that their education and treatment are comparable to those offered in the community; that discipline is appropriate and not harsh or unusual; that residences are home-like in that privacy is afforded, personal possessions are permitted, movement is not restricted by locked doors, and furnishings are like those found in community residences, etc. Advocates can help to

ensure rights of residents in areas such as voting, marriage, vocational training, and discharge from a facility.

Retarded Persons In The Community Adjustment Process

Residents leaving the institution and venturing for the first time into community living may be at a great disadvantage, since life in most institutions is vastly different from life in the community and most residents are poorly prepared to deal with these differences. Many residents who move to half-way houses, group homes, or apartments may not know how to use public or private transportation, shop in retail stores, budget their money, cook, or use community resources for leisure-time activities. If no one takes the time to help these people adapt to a new way of life, many may fail in community adjustment, not because they lack potential, but rather because there is a lack of basic assistance. A concerned advocate who offers counsel on an intermittent or continuing basis, can prevent the retarded person from being sent back to the institution because he failed in his one chance to make it on his own.

Community Residents

Mentally retarded persons who have never resided in an institution may require many of the same types of help needed by those

returning to the community from the institution. It is anticipated that the number of persons remaining in the community will increase rapidly because of governmental and parental pressures for programs and services (including residences) to be located there. While community living arrangements are more normal than isolated institutions, the need for advocacy services is still great due to the psychological isolation experienced by many mentally retarded people who remain with their families. There will be a continuing need to help these retarded individuals gain acceptance by the larger community. They will still need encouragement, or perhaps supervision in many cases, in starting and maintaining social contacts and learning to properly use leisure time.

Also, someone will be required to ensure that needed services, which are scarce in many communities, are provided, and that the rights of mentally retarded citizens are not being denied. The retarded person has a right to education, employment, and social acceptance just as other community residents do. Not everyone can be expected to live independently in the community, but most retarded individuals are capable of being semi-independent or independent if adequate training and proper living facilities are provided.

Advocates are particularly needed in poverty areas since the incidence of mental retardation is much higher there than in other segments of society. Some of the causes of this increased occurrence may be related to malnutrition, inadequate prenatal care, high frequency of physical injury, and understimulation of intelligence during the early years. Advocates who are matched to children from these areas should be thoroughly familiar with the cultures and environments of the children in order to best serve their needs. Preferably, the cultural background of the advocate should be similar to that of the child.

ADVOCACY AND THE DEVELOPMENTAL MODEL

Advocates are also in a good position to advance the Developmental Model (Wolfensberger, 1969) which holds that all mentally retarded persons are capable of growth, learning and development, even though, just like everyone else, they also have individual limits and rates of development. The three basic goals of the model (Roos, Patterson, McCann, 1970) include:

1) **increasing the mentally retarded person's control over the environment.** This involves giving the retarded person options for choices regarding such matters as food, clothing, recreation and occupation, as well as the freedom to experience risk and explore and interact with his environment and the people around him.

2) **increasing the complexity of the mentally retarded person's**

behavior. The advocate can help the protege develop more complex behavior patterns which will increase the retarded person's ability to cope with his environment. For example, the protege could move from being fed from a prepared tray to self-feeding in a family-style eating situation.

3) **maximizing the human qualities of the mentally retarded person.** The advocate can lead the protege, one step at a time, toward a more normal life, maximizing his human qualities, those qualities which are designated as culturally "normal" or "human". The advocate can help the protege develop social skills and utilize his full potential by providing experiences he might not otherwise have such as shopping, eating out in restaurants, or attending church.

Through the Developmental Model, the advocate can socialize the protege into the community by helping him to understand the laws that govern our daily lives, to learn consideration for other people and to respect their rights, and to call upon his own resources to help him work out difficult situations he may encounter.

One technique for reaching these goals is the Normalization Principle, developed first in Sweden and Denmark and enacted into the "Normalization Law" in Sweden in 1968. This model holds that even though a retarded person will never be "normal", he should live in as normal an environment as possible, and follow as normal a "rhythm of life" as he can. He should grow and learn and work and enjoy as much privacy and freedom as possible. This Principle also implies that the protege should be exposed to experiences, both good and bad, which all children have in common . . . satisfaction, happiness, fulfillment, rejection, loss, failure. In other words, an effort is made to normalize the physical and social environment of the child.

Because the advocate is a volunteer to a person, and not to an agency or program, he is best suited to serve the human needs of his protege, helping him achieve his maximum potential as an individual.

ROLES OF ADVOCATES

In order to benefit his protege, an advocate's role will vary according to the needs of the retarded person. For example, a semi-independent retarded young person who is working to support himself and living in a group home may need only occasional **practical** help in such areas as the preparation of income tax forms or the upkeep of his car. Another retarded young person may be living at home where all his physical needs are being met, but, due to a large number of other children in the family, he may not be receiving the warmth and individual companionship he needs. In this case, an advocate would simply function on an **emotional** level. In different circumstances, a retarded child may have been

over-protected by his family, and may need an advocate to provide both friendship and practical guidance in helping him relate to the community as he grows up.

There are several levels and combinations within the wide scope of advocacy roles which enable an advocate to be matched most successfully with a protege whose interests are similar and whose needs are not beyond the capability of the advocate to fill. Advocacy roles can vary from short-term to long-term or even lifelong. They can range from informal friendship arrangements to more formal legal ties such as those found in guardianship. An advocate can be involved in taking care of the practical needs or the emotional needs of a protege, or a combination of both.

While the heart of the Citizen Advocacy model is the one-to-one relationship, advocates can also act in other combinations. Examples of this could include one advocate watching over two or more proteges, possibly meeting the practical needs of one, and the emotional needs of another; or an entire family sponsoring one protege. Or a young married couple could be advocates for a young retarded couple planning to marry.

As you can see, there are many combinations; and this flexibility is one of the biggest assets of the Citizen Advocacy concept for retarded children. It is a flexible program which can be molded to include many types of advocate-protege relationships as long

as the basics are left unchanged and untampered with by agencies or funding sources which could cause a conflict of interests.

To give the reader a better understanding of the various advocate roles, we will break them down into several groups most suitable to Citizen Advocacy and define the major functions of each type of advocate.

The Advocate-Companion — This form of advocacy involves an informal relationship which deals primarily with friendship and filling the emotional needs of the protege.

The Advocate-Adviser — This is a slightly more complicated relationship because two situations may exist: 1) the advocate may meet only the practical needs of the protege, or 2) the advocate may fill both the practical and emotional needs of the protege. The latter alternative is much more common, because it is logical that in helping a protege learn the practical aspects of basic living, the advocate also becomes a friend to the retarded person. For example, a mentally retarded young woman planning to marry may need a female advocate who can help her learn the mechanics of homemaking and the responsibilities involved in marriage, and at the same time, serve as her confidant as well.

Guardian — Guardianship is a formal, legal arrangement where the advocate looks after the needs of the protege without taking him into his own family. This kind of relationship is usually based on filling practical needs, but may also entail some emotional involvement. For example, a retarded child whose parents are presently unable to ensure that he receives proper services and benefits, or who want to provide for him after their death, may want to appoint an advocate-guardian for their child.

Conservatorship and Trust — These two roles are primarily concerned with the administration of a dependent person's estate and deal more with property rather than with the person himself. Conservatorship can be carried out by trust companies, banks, private individuals, special committees, etc. While a conservatorship is wholly a practical role, a trust, on the other hand, can also concern itself with the welfare of a person in general although it is not likely to equal the amount of personal involvement implied by a guardianship arrangement.

Toward the Parent Role—At the end of the advocacy continuum naturally fall the foster or adoptive parent relationships that sometimes develop out of the advocacy roles described above. Foster parenthood is a formal bond in which a child is taken into the home for a period of time. Foster parents are usually paid for their services, and they meet both the practical and emotional needs of the child.

Adoptive parenthood is a formal, legal arrangement in which the

parents serve the child as if he had been originally born to them. He may even take on the last name of the family, and become a real part of their lives. While Citizen Advocacy relationships do not generally end in this kind of arrangement, there have been several cases where the advocate and his family became so close to the protege that they decided to take him into their family.

SPECIAL ADVOCACY ROLES

In addition to these advocacy roles, there are several special roles which an advocate may fill. One of the most significant of these is the **Youth Advocacy** function. Young people can form a vital part of the movement because their qualities of idealism, energy, and impatience with bureaucracy make them highly effective advocates, and they can provide peer-group relationships that are often missing from the lives of retarded persons. When the Youth Advocate reaches the age of legal accountability, he may wish to expand his role to include other facets of involvement that require his legal classification as an adult, such as initiating a court action on behalf of the protege.

The Emergency or Stand-by Advocate is one who serves on a stand-by basis and helps only in emergency situations which may be of major importance in the protege's life. Such a crisis may only happen once; yet, if the retarded person doesn't have someone to turn to in this emergency, the entire course of his life may be altered. This role is best filled by an interested and well-qualified citizen who wants to help, but due to his or her work and family situation, etc., is unable to become involved with a protege on a regular basis.

A hypothetical situation of the value of such a relationship follows: a retarded young man has car trouble, and when a patrolman stops to give assistance, he decides (because he is unfamiliar with or uninformed about mental retardation) that the man's behavior is suspicious. The young man, who is frightened and flustered, is unable to state his case clearly, so the policeman decides to take him down to the station. In such a critical event, a Stand-by Advocate, who can be called by police who are aware of the advocacy office, could help straighten out the mistake as well as aid the protege to understand what has happened and why, so he can deal with such situations better in the future. The advocate may never see the protege following this event, but he will have served as an important person in his life.

As we mentioned earlier, it is not advisable for professionals to be providing services to a client while simultaneously acting as his personal Citizen Advocate because conflicts of interest may hinder the protege from receiving the most benefit. As private citizens, professionals can serve as regular advocates to proteges in their leisure time, and they can also become involved in the pro-

gram in several other ways as **Associate Advocates.** These Associate Advocates can provide support for the program by serving on Advisory Committees, helping the program gain acceptance in the community, and being on call for advice and back-up in their individual areas of specialization. They can also act as referral agents for the program, keeping their eyes open for retarded persons who could benefit from Citizen Advocacy. And they can work within the framework of their own agencies to try to change and improve services for the retarded clients they serve.

SUPPORT AND REINFORCEMENT FOR THE ADVOCATE

One of the major differences between the Citizen Advocacy approach and the traditional volunteer program is that a different kind of supportive structure is provided by state and local offices and their committee systems.

Local Offices

In order to provide options and resources for advocate reinforcement, and to assure continuity, it is necessary to set up Citizen Advocacy offices on the local level. These offices protect both the protege and the advocate, and make the relationship as beneficial to both as possible.

There are several major points which should be understood regarding these offices. First, they should be independent in location and funding. This means that sponsorship should probably come from Associations for Retarded Citizens, other groups for handicapped people, local service clubs or other such organizations. The office should not be directly funded by local service-delivery agencies, however, because the problems listed previously in the "Protective Service Agencies" section could hinder the office from doing its most effective work.

It is best to have a full-time coordinator for this local office who can initially devote the majority of his or her time to promoting the advocacy schema in the community and making sure of its ongoing support and success. It is the coordinator's responsibility to secure additional staff members if necessary, to recruit potential advocates and proteges via publicity campaigns in local media or through Speakers' Bureaus, to screen the advocate-candidates carefully, orient them to the program, match them with suitable proteges, and supervise the ongoing relationship. The coordinator should brief the advocate on resources of a legal and professional nature which are available to him. It is also the coordinator's responsibility to review the relationship periodically based on his own perception of the situation and its needs.

In the early part of the establishment of the local office, it is important that an Advisory Committee for the local program be appointed from community professionals, interested laymen, and representatives from sister organizations for the handicapped. This committee will be invaluable in helping the office to deal with problem situations, and by acting as a resource body for the advocates themselves.

It is also important that the coordinator plan his publicity and recruitment strategies so that groups of people not usually involved in such volunteer programs can be reached. A special effort should be made to recruit advocates and proteges from minority and poverty groups.

State Offices

If there is the initial intention to start several local programs in a state, it is most beneficial to the program to first establish a state advocacy office. This office reinforces its local branches through coordination of their activities; fund-raising efforts; dissemination of new materials and aid in publicizing activities of local offices, both among themselves and in their own communities; legal back-up; and training of coordinators.

It is the responsibility of the state office to keep abreast of the current law suits involving mentally retarded people both on a state and national level, and to inform their local offices of legislation affecting their operation. There should be interchange between the state offices and the national Child Advocacy Project coordinating office so that mutual problems and solutions can be shared.

The state office can also serve as a resource center for persons from local programs or other interested parties who want to learn more about Citizen Advocacy for mentally retarded children. Instructional and information materials should be made available to local coordinators and their advocates. If, initially, there are to be only one or two local pilot programs in a state, it is possible to set up the state office at a later date when the program has been generally accepted around the state and other commitments have been obtained for local projects.

THE CURRENT THRUST TOWARD ADVOCACY

The advocacy outreach effort is well-timed to fit in with current trends toward consumer representation and intensified public interest and participation in securing civil and human rights for all handicapped people. Two events focused national attention on the problems of these persons. The first was a meeting in 1970 of the Joint Commission on Mental Health of Children during which members recommended that a national advocacy network be es-

tablished to ensure that needed programs and services are available to every child. In 1971, the need for such a system was again stressed by participants in the White House Conference on Youth.

Recent priorities set forth by the federal government in terms of legislation, funds for demonstration projects, etc., also endorse the movement toward advocacy and a more personalized approach in the education and treatment of handicapped persons, including the mentally retarded.

Other factors that have contributed to the idea that a viable advocacy system is needed include the federal emphasis on deinstitutionalization of mentally retarded persons, and the attention being given to developing community-based services to take care of their needs as they adjust to community life. In reference to these two priorities, President Richard M. Nixon stated in his November 16, 1971, message to the American people that a major national goal

should be "to enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community". Prior to that on January 9, 1970, he said, "The important thing is to integrate the retarded as much as possible into normal activities and services rather than separate them". It can be clearly seen that Citizen Advocates can form a vital link between the previously institutionalized person and the community, thus helping fulfill these goals.

For those mentally retarded persons who remain in institutions, there has been an increasing national concern over improving conditions in public residential facilities and setting up standards which must be met by these institutions. Recognizing the need for cooperation between agencies in this endeavor, the American Association on Mental Deficiency (AAMD) formed in 1966 the National Planning Committee on Accreditation of Residential Centers for the Retarded, made up of representatives of AAMD, the Council for Exceptional Children, United Cerebral Palsy, American Psychiatric Association and NARC. These five organizations founded the Accreditation Council for Facilities for the Mentally Retarded with the purpose of improving services provided for mentally retarded persons through a national voluntary program of accreditation for residential facilities. Members added since that time include the American Academy of Pediatrics, American Nurses' Association, American Psychological Association, and the National Association of Private Residential Facilities for the Mentally Retarded. Accreditation of residential facilities began in early 1972, and additional standards have been developed for non-residential services.

Emphasis is also being placed on equal treatment and education of handicapped persons. At the time of a 1971 survey, approximately 64% of the mentally retarded children in the United States were not receiving the education to which they are entitled (NARC Operational Research Report, 1971). In 1971, the Pennsylvania Association for Retarded Children decided to do something about the problem, so they filed suit, affirming that retarded children have the same rights to education that other children have, and charging the state with the responsibility of providing this previously denied service. Since the vast majority of all handicapped children can live productive lives if given the proper training, these concerned parents felt that their children's rights were being denied if they were not receiving a full education. Federal courts agreed, and the state began the process of implementing a plan to integrate all these children into their school systems. Some will be placed in special classroom settings while others will be in regular classes. This class action suit set the precedent for many others, and thus, educational rights for handicapped children are being gained all across the country.

Besides the advantage for these children with special needs who are now, for the first time, being given equal rights with their peers, the "regular kids" in the classroom are learning as well — learning to accept and understand differences in human beings as a normal part of daily living.

As a Citizen Advocate, you will have the opportunity to get in on the ground floor in respect to this movement toward more active citizen participation in such matters. You can make life better for a retarded person in your community. Unless something is done, mentally retarded persons will continue to be viewed as "sub-human," and they will continue to have certain inherent rights, privileges, and needed services denied to them.

These retarded people may never enjoy the benefits of a full life if you remain apathetic. Indifference is an impediment to progress, and "waiting for someone else to do it" is an outdated, ineffective way of dealing with human problems. Without your involvement, much potential will be wasted among handicapped persons who could live productive lives if given the opportunities to do so. Human ecology is a challenging area of service, and the volunteer will gain a great deal from his role as an advocate.

The interested reader is referred to three additional books containing in-depth information on advocacy, including Book II on "Implementation of Citizen Advocacy Through State and Local ARCs", Book III on "Effective Advocacy", and Book IV on "Youth Advocacy".

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